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ABSTRACT

The first of five papers written by the Ohio Developmental Disabilities Planning Council's Deinstitutionalization Task Force Project, this document focuses on the role of institutional services. Following a brief summary of planning principles (least restrictive alternative, right to services, normalization, equal justice, respect for human dignity, and developmental orientation), the document reviews planning processes and strategies. Each of 10 potential system barriers (prior fiscal investment, employee rights, parent concerns, public attitudes, community resources, funding resources, legal concerns, coordination/management, individual rights, and community program capacity) is addressed in terms of consequences, solution strategies, and conclusions. Recommendations include increased funding to expand local services, cost-sharing between state and local community, and increased planning efforts geared to developing integrated community-based services. (CL)

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POSITION PAPER NO. 1

The Future of Institutional Services in Ohio:

Do We Need to Plan for Institutional Services?

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The Future of Institutional Services in Ohio:

Do We Need to Plan for Institutional Services?

Prepared by
The Institutional Services Subcommittee
Deinstitutionalization Task Force

Wade Hitzing, Subcommittee Chairperson
Ronald E. Kozlowski, Project Coordinator

The contents of this paper reflect official policy and positions of the Ohio Developmental Disabilities Planning Council.

December, 1983

"LONG RANGE PLANNING DOES NOT DEAL WITH FUTURE DECISIONS, BUT WITH THE FUTURE OF PRESENT DECISIONS."

Peter Drucker

This paper reflects the official position and policy of the Ohio Developmental Disabilities Planning Council. The development of this paper was supported by funds made available through a grant from the Ohio Department of Mental Retardation and Developmental Disabilities, authorized under P.L. 95-602 to further the attainment of the goals and objectives of the Ohio Developmental Disabilities Planning Council.

The contents of this paper do not necessarily reflect the position or policy of the Ohio Department of Mental Retardation and Developmental Disabilities, and no official endorsement of the above agency should be inferred.

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PREFACE

Changes in the philosophy of services and a growing concern for the rights of persons with developmental disabilities have led to a national deinstitutionalization movement. Thus, the service system for Ohio's citizens with developmental disabilities is in a period of transition as the state moves from an institution-based to a community-based service delivery model. Although the deinstitutionalization movement has increased the move toward community-based services, numerous constraints continue to challenge this effort. With the transition in progress, the development of long- and short-term service development plans is critical to the evolution of a cohesive system that uniformly provides appropriate and adequate services. Identification of the nature and shape of the desired service system, the recognition of existing and potential constraints, and the development of an effective planning process must occur to assure that quality services are available now and in the future.

It is within this context that the Ohio Developmental Disabilities Planning Council created the Deinstitutionalization Task Force Project. The purpose of the project was to establish and provide staff support to a Deinstitutionalization Task Force, which was formally constituted in March 1981. The Task Force, composed of representatives from various agencies and consumer groups (see inside back cover), was charged with the responsibility to identify major issues related to deinstitutionalization and to develop recommendations for increasing the availability of appropriate services to persons with developmental disabilities.

Given its charge, the Task Force had two major options in terms of where to focus its attention: (1) on the nature or structure of the service system or (2) on the service process. Because of the scope and complexity of the issues related to deinstitutionalization, the Task Force decided to focus on the nature or structure of the service system. This approach was chosen because (1) an appropriate structure is a necessary condition for the development of quality, appropriate services and (2) many process guidelines and safeguards are already present in rules and regulations. By focusing on the structure of the service system, the Task Force could then develop a plan containing: (1) a broad outline of the proposed service system and (2) a broad outline of proposed planning strategies.

The Task Force considered this option as most consistent with the Developmental Disabilities Planning Council's advocacy function, in that the development of a broad outline of the proposed service system facilitates systemic change. Long-range service goals define how things "ought to be" and can be used to guide short-term transition planning.

The Task Force initially sought to identify the various legal and philosophical principles in the field of developmental disabilities and to define with a high degree of clarity the actual issues surrounding deinstitutionalization. These deliberations were based on experiences in Ohio and augmented by the experiences of some of the more active state programs outside of Ohio. The basic concepts that emerged were used then to guide the planning process.

This led to the second step, which was to apply these concepts to a service system for persons with developmental disabilities. The Task Force selected the following broad areas in which to concentrate its efforts: (1) the role of institutional services (2) residential services (3) adult services (4) informal and formal supports, and (5) administrative structure and finance. To provide broad-based professional and consumer input in addressing these general topical areas, a subcommittee structure was established. The following subcommittees were constituted by the Task Force:

- o Institutional Services Subcommittee
- o Community Services Subcommittee
- o Prevention of Institutionalization Subcommittee
- o Finance Subcommittee

This structure essentially provided a two-tier review process. Each subcommittee was charged with the initial development of a position paper on a selected topic. The Community Services Subcommittee was charged with initial development of position papers on two topics. The papers were then all submitted to the Task Force for review and/or modification, and subsequently adopted as official position papers of the Task Force. The five position papers provide statements of program philosophies and service strategies that can be used to develop quality services for persons with developmental disabilities. Each position paper contains a series of broad recommendations that the Task Force believes should be used in developing specific implementation plans.

The Task Force believes that the position papers describe a realistic direction for Ohio's service system and should be used as roadmaps for developing quality services for persons with developmental disabilities.

Papers in the series include:

Position Paper No. 1:	THE FUTURE OF INSTITUTIONAL SERVICES IN OHIO: Do We Need to Plan for Institutional Services?
Position Paper No. 2:	RESIDENTIAL SERVICES IN OHIO: The Need to Shift from a Facility-Based to a Home-Centered Service System
Position Paper No. 3:	FUTURE DIRECTIONS IN ADULT SERVICES
Position Paper No. 4:	PROMOTING QUALITY COMMUNITY LIVING THROUGH FORMAL SUPPORT SERVICES AND INFORMAL SUPPORTS
Position Paper No. 5:	FUTURE DIRECTIONS IN ADMINISTRATIVE STRUCTURE AND FINANCE: PREREQUISITES FOR COMMUNITY-BASED SERVICE.

Nisonger Center
The Ohio State University

Ronald E. Kozlowski
Project Coordinator

ACKNOWLEDGMENTS

The Deinstitutionalization Task Force Project was originally established through a letter of agreement between the Ohio Developmental Disabilities Planning Council, The Department of Mental Retardation and Developmental Disabilities, and the Ohio State University Research Foundation (Nisonger Center) to identify issues and develop recommendations relative to deinstitutionalization in Ohio. The products of the Task Force are the result of a collaborative effort by various individuals, representing a variety of organizations and agencies, who participated on the Task Force or its subcommittees, or otherwise provided assistance in developing the various position papers. Forty-two individuals, representing thirty-three organizations and agencies, contributed to the development of the five papers. Appreciation is extended to those individuals, who graciously gave their time, patience, and expertise.

A special mention is made of the sincere efforts that were put forth by Dr. Jerry Adams, who conceived the project and devoted tremendous personal energies toward making project activities viable. Succeeding Dr. Adams, Dr. Denis Stoddard also devoted much personal energy in supporting the project. Dr. William Gilbert and Dr. Henry Leland (Co-chairpersons) guided the Task Force through its deliberations and saw to it that the Task Force completed its tasks. Appreciation is also expressed to the Ohio Developmental Disabilities Planning Council for recognizing the significance of this project and providing funding for its activities, and adopting the position papers produced by the Task Force as official policy and position statements of the Council.

DEINSTITUTIONALIZATION has been defined in various ways. The term has been used to describe: (1) movement of residents out of state institutions; (2) development of community-based programs; (3) prevention of institutional placements; and (4) institutional reform. Sometimes, it has been defined as a process and, at other times, as a goal or objective.

OHIO AT A CROSSROADS

Ohio has played a part in the national deinstitutionalization movement. The average number of developmentally disabled persons living in institutions in Ohio decreased from 10,017 in 1967 to 4,500 in 1982, a decrease of 5,517 or 55%. However between 1968 and 1982, the number of state-operated residential institutions increased from 7 to 13; as of June 1982, 5 of Ohio's state-operated residential facilities had populations over 300 each.

Concurrent with the decline in the number of institutional residents has been an effort to upgrade the quality of services provided by state institutions. In part, the Medicaid Program (Title XIX) has provided both fiscal incentives and higher program standards for institutional services. The state has sought to meet institutional Intermediate Care Facility-Mental Retardation (ICF/MR) standards to capture federal funds, thus sharing financial costs with the federal government. Although the institutional population has been declining, the necessity for upgrading institutions to meet Medicaid standards has resulted in an accelerated flow of state dollars into Ohio's institutions.

The deinstitutionalization movement in Ohio has resulted in rapid growth of community-based services. For example, enrollment in County Boards of Mental Retardation and Developmental Disabilities programs increased from approximately 9,675 in 1967 to 23,098 in 1982, an increase of more than 139% (Ohio Department of Mental Retardation and Developmental Disabilities, 1982). The number of community beds licensed by the Department of Mental Retardation/Developmental Disabilities increased from 700 in 1971 to more than 6,656 in 1982. As of December 1982, there were 814 licensed community residential facilities in Ohio.

Although the deinstitutionalization movement has increased the growth in community-based services, numerous constraints continue to challenge this trend. During this transition period, the development of long- and short-term service development plans is critical to the evolution of a cohesive system to provide appropriate and adequate services uniformly. The identification of the nature and shape of the desired service system, the recognition of existing and

potential constraints, and the development of an effective planning process must occur to assure that quality services will be available now and in the future.

BASIC PLANNING PRINCIPLES

Before considering the role of institutional services, it is important to clearly delineate some basic planning principles. The specification of these principles, or planning assumptions, will provide a listing of positive criteria to assess both short- and long-term planning decisions.

LEAST RESTRICTIVE ALTERNATIVE

The principle of least restrictive environment requires that the living environment be the most age and culturally appropriate for meeting a person's needs for supervision and training, without imposing unnecessary modifications or denial of personal rights. A further consideration is that the selection of a particular living situation must be based on the person's needs and wishes—not just on the options currently available in the service system.

There is a relatively simple test for dealing with the issue of determining least restrictive alternative. In trying to decide whether a specific living situation fits the criterion of least restrictive alternative, one must ask whether there are examples of persons with similar needs being appropriately served in other, less restrictive, settings. This type of test was critical to the landmark Pennhurst Case (Laski, 1980). The basic strategy of the plaintiffs was to show that, for each resident living in Pennhurst (a restrictive setting), there was a person with similar needs who was being appropriately served in a less restrictive setting. After being presented with many such examples, the judge concluded that an institutional environment was not necessary to meet the resident's needs — in that each Pennhurst resident had a "functional twin" living in an appropriate, less restrictive, community-based setting.

It is important to point out that application of the principle of least restrictive alternative does not mean that Ohio will be able to provide all persons with age and culturally appropriate, typical residential settings. However, application of this principle does require that placement of a person in settings other than these be proven as necessary to meeting the person's needs. In other words, the basic planning assumption should be that all individuals will live in small, well-integrated, positively valued settings. Any deviation from this strategy, toward more restrictive settings, can only be undertaken after proof that the person's needs cannot be met in less restrictive alternatives.

RIGHT TO SERVICES

The assumption of a right to services concerns the right of a person to services or treatment that promote growth toward increased independence and competence.

While a person may benefit from institutional programs, it is questionable whether such programs provide an adequate treatment or service environment. Given that the ultimate goal for all persons is for them to live as much as possible in a complex, heterogeneous, community-based setting, the adequacy of any institutional setting must be questioned. How does the congregation of large numbers of persons with developmental disabilities in physically and socially segregated settings contribute positively towards enhanced independence and competence?

NORMALIZATION PRINCIPLE

Over the past 5 to 10 years, many institutions have attempted to "normalize" their services and settings. Beyond cosmetic changes, more serious attempts, such as cottage development, have been made. (It is important to note that another important factor in cottage development was the attempt to qualify for Medicaid funds.) While it would be difficult to deny that a 16-bed cottage is an improvement over a 60-bed institutional ward, such cottages clearly do not provide a reasonably typical, positively valued residential setting. Appropriate application of the principle of normalization should result in the development of residential services that ensure a person's presence and participation in the community. Groups of cottages located on the grounds of a state institution are not consistent with this approach.

EQUAL JUSTICE

Adherence to the concept of equal justice requires that persons with developmental disabilities be provided services and supports that will allow equal opportunity for growth and development. Each person with developmental disabilities, as do other members of society, has a right to receive services from publicly supported programs. The arguments used with respect to Right to Services are relevant here also. In a variety of places across the United States, persons with severe handicaps are being served in quality, integrated community settings (Apolloni, Cappuccilli, & Cooke, 1980; PCMR, 1978). The principle of equal justice requires that Ohio's long-range plans be based on the assumption that all persons can participate in community life.

Planning Principles

RESPECT FOR HUMAN DIGNITY

While a respect for human dignity may seem to be more abstract than the other planning principles, it is still extremely important. Human dignity is closely related to a person's ability to make choices, select and maintain possessions, to be treated with respect, to live in surroundings that foster individuality and allow for privacy, to participate in the development of their own service plan, and to receive services and supports tailored to their own unique needs. Most persons have characteristics and competencies valued by others. They can usually advocate for themselves and can, therefore, gain at least a minimum of dignity and respect.

Except in very limited ways, persons with severe handicaps cannot gain the same degree of dignity and respect by their own actions. It is, therefore, extremely important that they be treated with respect and served in settings that are as positively valued as possible.

DEVELOPMENTAL ASSUMPTION

Traditionally, mental retardation and other forms of developmental disabilities have been looked upon as "health problems", and services have been structured on a medical model. Many needs, such as communication, personal skills, homemaking, and social skills, were attributed to the person's developmental disability and viewed as being a sickness or physical problem, remediated or met by medical settings and approaches, medical processes, and medicines. Persons with disabilities were perceived as having limited potential. In part, institutional services have been based on the medical model.

However, since knowledge about developmental disabilities has expanded, it has become clear that a developmental disability is not primarily a health problem. A disability is not the same as an illness nor, very often is there a cure. Developmental disabilities are conditions, stemming from physiological or psychological handicaps that significantly curb or affect a person's development. If developmental disabilities are a developmental problem, then they must be approached as such. Human beings, by their nature, grow, change, and develop; persons with developmental disabilities are not exceptions. The only difference is that persons with developmental disabilities need specialized, sometimes long-term, help to develop as fully as possible.

The developmental assumption is considered, by most authorities, to be a desirable approach to serving persons with developmental disabilities and serves as a basis for valid service development and delivery. The developmental assumption is based on two principles.

- Life as Change: Human beings are in a constant state of change from the time of conception until death. (The assumption that persons with developmental disabilities are often physicially and psychologically fixed or unchanging is, in effect, to deny their humanity; all persons, regardless of the type or degree of handicap, have the potential for positive growth.)

- Modifiable Development: The rate of development is influenced by interactions of many internal and external factors, including inherited characteristics, health, and the external environmental setting (The rate, direction, and ultimate level of development can be influenced through teaching, and by utilizing and controlling certain physical, psychological, and social aspects of the environment.)

A primary goal of programs for persons with special needs should be to increase the adaptive behavior and general competencies of the individual by modifying the rate and direction of behavioral change. Persons with developmental disabilities should be approached from the standpoint of being capable of growth, learning, and development. They should be considered in a state of constant change that can be significantly influenced by conditions imposed within the environmental setting. Persons with developmental disabilities have normal developmental stages of infancy, childhood, adolescence, and adulthood. Within each stage, different needs are emphasized. Although these stages may be delayed in varying degrees, persons with special developmental needs should not be subjected to socially imposed perceptions that limit growth.

The primary implication of the developmental assumption is that programs be oriented toward the individual, and that program goals be dynamic and individually defined. Residential programs should be designed to be as growth-enhancing and supportive of learning as possible. Institutional settings, which tend to congregate large numbers of persons with special needs and segregate them from normal community activities, are not consistent with the developmental assumption.

EFFECTIVENESS AND ECONOMY

The issue of effectiveness has already been dealt with, at least in part, in the discussion of the Developmental Assumption. It is paradoxical that one of the most frequently cited reasons for institutionalization, that it provides effective service and treatment, is not supported by research findings (McCarver & Craig, 1974; Pilewski & Heal, 1980). The only real justification for using an institution, as a training center, is to prepare persons to live in an institutional

setting. Recent research shows that it is very important, especially for persons labeled as severely and profoundly disabled, to participate in training programs that are as similar as possible to normal community settings (Martin, Rusch, & Heal, 1982). This is especially important for persons with mental retardation because of their difficulty in generalizing from the original learning environment to other settings.

It is ironic that the other reason for the development of state institutions, economy of service delivery, is not supported by cost data. A number of studies have shown that quality, community-based programs can be provided at no more, and in some cases less, cost than institutional care (Boggs, 1981; Lakin, et.al., 1982; Touche-Ross, 1980).

However, there is an important complication to the economy analysis. Cost incentives and disincentives must be analyzed separately for each of the major "actors" in the deinstitutionalization movement. Research has shown that the financial burden of maintaining individuals in state-operated facilities falls predominantly to the state and federal government, while the financing of community residential programs shifts more to local government resources in tandem with increased contributions from residents/families and other local sources (Wieck & Bruininks, 1980).

Another important cost consideration is the maintenance of a dual residential system, consisting of both state-operated and community programs. The dual system results in separate, and uncoordinated planning and budgeting for residential services; overuse of costly institutional services; and diminished possibility of utilizing scarce resources to develop quality residential programs.

Although cost considerations are important, it is more important not to lose sight of humanitarian considerations in providing community-based residential programs.

PLANNING PROCESS

The Institutional Services Subcommittee, in analyzing the need to plan for institutional services in Ohio, first attempted to specify and analyze the long-term goal of institutional services. The intent was to develop a standard against which individual needs, as well as system constraints, could be assessed. Rather than considering a variety of possible goals, the subcommittee decided to analyze only the most desirable or ideal goal. Definition of the concept of "desirable or ideal" was guided by the previously described planning principles (normalization, least restrictive alternative, etc.). Simply stated, the subcommittee's desirable or ideal long-term goal for institutional services was that "All persons with developmental disabilities will have their

needs met in small, well-integrated, community-based settings."

With this long-term goal as a standard, the subcommittee developed a working assumption to guide its planning process: "Ohio can begin to plan for a community-based service system, for all its citizens with developmental disabilities, that does not include institutional residential services."

It should be noted that while the primary focus of the subcommittee was on an analysis of Ohio's developmental centers, to a lesser degree it also discussed community-based institutional services such as nursing homes and large congregate facilities. The subcommittee did not set a specific bed size as a definition of an "institutional residential program." However, for purposes of analysis, residential programs that congregate more than six to eight individuals were considered institutional. Therefore, another way to state the working assumption is:

> "OHIO CAN BEGIN TO PLAN FOR A SERVICE SYSTEM, FOR ALL ITS CITIZENS WITH DEVELOPMENTAL DISABILITIES, THAT HAS RESIDENTIAL ALTERNATIVES ACCOMMODATING NO MORE THAN SIX TO EIGHT PERSONS, UNLESS JUSTIFICATION IS PROVIDED THAT LARGER SETTINGS ARE REQUIRED TO MEET THE PERSON'S SERVICE NEEDS."

The first major issue addressed was whether or not there were any individual needs that could be met only in institutional settings (individuals could not be served in small, integrated, community-based settings). The consensus was that even the most profoundly handicapped, medically fragile person could be served outside of an institution—if sufficient community services and supports were provided. This position represents a significant change from earlier analyses, which often resulted in statements such as:

> "Because of Mary's profound level of mental retardation, she must live in an institution."
>
> "Because of Jim's high seizure rate, he will require intensive institutional services."

Historically, individual characteristics—needs, deficits, etc. - have been used to justify the continuation of institutional services.

However, concluding that there are no individual needs that require institutional services does not automatically result in a call for an end to institutional services. Although there are no individual-based needs that require continued institutional services, perhaps there are system issues that

function as major barriers to an eventual phasing out of all institutional services. There may be other system factors, such as cost-effectiveness, personnel, resources, etc., that require continuation of some institutional services. Adoption of the planning assumption does, however, clearly require that if we ultimately plan for long-term continuation of some institutional services, we do so not because it is the only way to meet the person's service needs, but because Ohio cannot provide sufficient supports and services for all persons with developmental disabilities to live in community-based settings. This does not make such a planning decision right or wrong, it simply makes it clear why it was made.

The planning strategy used by the subcommittee in developing the positions outlined in this paper is shown in figure 1.

POTENTIAL SYSTEM BARRIERS

Each of the following system constraints was selected for one or more reasons: (1) it represented a barrier toward developing a plan for phasing out institutional services, such as lack of funds or personnel resources; (2) it represented a potential problem that could develop if the plan was adopted, and institutional services were gradually phased out. Examples of the latter problem include negative fiscal impact on local communities, and loss of state jobs. The possible consequences of each barrier or potential problem are presented, along with potential solution strategies.

PRIOR FISCAL INVESTMENT

Ohio has an enormous fiscal investment in institutional services, especially in terms of property, buildings, and bond indebtedness. In addition, the presence of state facilities has an enormous impact on local economies, particularly in rural areas.

Consequences

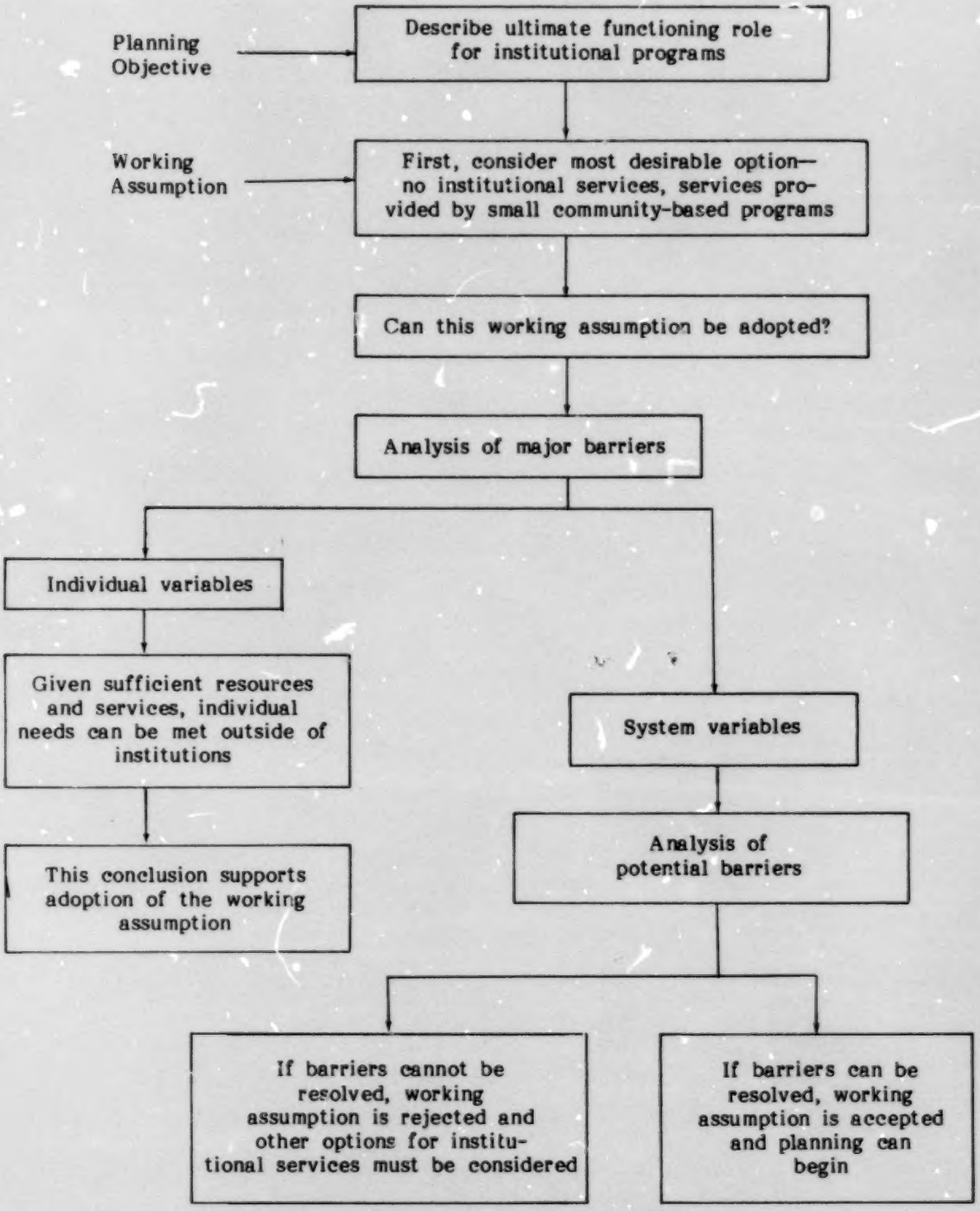
If alternative uses are not found for buildings and property, the phasing out of institutional services could be perceived as a "waste" of resources. This could result in significant public protest and political repercussions. If institutional services are phased out prior to the final "pay-off" of the bond indebtedness, the state will have the expense of buildings without any way to generate the resources to pay for them.

Solution Strategies

There is no overall strategy that can be used to deal with all prior fiscal investments; an urban institution might

Figure 1

PLANNING STRATEGY


Planning Objective
Describe ultimate functioning role for institutional programs
Working Assumption
First, consider most desirable option—no institutional services, services provided by small community-based programs
Can this working assumption be adopted?
Analysis of major barriers
Individual variables
Given sufficient resources and services, individual needs can be met outside of institutions
This conclusion supports adoption of the working assumption
System variables
Analysis of potential barriers
If barriers cannot be resolved, working assumption is rejected and other options for institutional services must be considered
If barriers can be resolved, working assumption is accepted and planning can begin

easily be sold or renovated for another purpose, but fewer options exist for rural institutions. Given the broad range of demographic variables, each local community will have to develop specific plans to deal with this issue. General suggestions discussed by the subcommittee included:

- o Changing the present bonding structure to allow more flexibility
- o Using facilities for other public purposes, to offset some of the indebtedness
- o Selling, leasing, or giving away properties
- o Using developmental center facilities as community regional centers (diagnostic centers, workshops, rural medical centers, etc.), but not for long-term residential placements

Conclusion

Given the gradual nature with which institutional services would be phased out, prior fiscal investment is not an immediate problem. Gradual phasing out will also allow time for local communitiues to develop facility-specific plans. This is not a major barrier that precludes adoption of the working assumption.

EMPLOYEE RIGHTS

A large number of individuals are employed in state-operated developmental centers. In addition, many other people are employed in community-based institutions, such as nursing homes. Phasing out of institutional services will result in a loss of these jobs.

Consequences

The loss, or simply threat of loss, of institutional jobs, and the resulting impact on local communities, especially in rural areas, could result in lobbying and subsequent political action. This type of protest could, at least temporarily, disrupt the movement toward deinstitutionalization. It will be very difficult to protect the rights of institutional employees while, at the same time, ensuring that persons with developmental disabilities do not remain institutionalized simply to maintain job positions.

Solution Strategies

Gradual phasing out of institutional services will allow for natural job attrition, which will greatly reduce the number of people who might be "forced" to leave their jobs. Retraining and relocation programs will also allow many employees to transfer to job positions created in local communities. It is also possible that local jobs could be maintained in those facilities sold or converted to other uses. Other possible solutions include:

- o Providing temporary financial parity between institutional and community-based jobs
- o Developing funding transition programs, whereby the state shares at least initially in funding for new community job positions.
- o Transferring state civil service employees to local civil service systems
- o Providing job placement programs

This is, potentially, one of the more explosive barriers. The transition to a community-based system will benefit persons with developmental disabilities, but it will, at the same time, have a negative impact on those rural communities that have come to rely on institutional funding.

Conclusion

Employee rights is not a major barrier that will preclude adoption of the working assumption. However, it may become a major barrier if the state does not initiate efforts to address this issue equitably.

PARENT CONCERNS

Initially, some parents/guardians of persons with developmental disabilities are concerned that:

- o Institutions may be the safest place for their son or daughter.
- o Community programs may not endure; they can't trust that such programs will be able to provide life-long services.

Consequences

As with institutional employees, parent groups might become more politically active and work to stop the deinstitutionalization process.

Solution Strategies

A variety of strategies could be used to allay parental concerns. The most effective way to meet parental concerns is the development of a comprehensive, adequately funded, life-long, community-based service system. Historically, we have seen "The State" as the final, if not primary, residential service provider. We have also equated residential services with institutional living. Over time, parents will come to rely in the same way on their local system and realize that adequate residential services can be provided in the community. Other strategies include:

- o Developing a stable, adequate funding base for community-based services
- o Clearly communicating that the move to community-based services does not mean that the state is relinquishing its responsibility to ensure adequate service delivery
- o Maximizing parent involvement in planning, placement, and long-range follow-up processes
- o Providing an on-going, comprehensive, and permanent mechanism for case management and, if necessary, guardianship

The preceding solutions are proposed in an attempt to increase parents' acceptance of community-based services. However, the state should also clearly communicate that there is no legal or value-based reason to provide a more restrictive setting than is necessary to meet a person's needs. No one has a right to institutional services, if their needs can be met in less restrictive settings.

Conclusion

Parent concerns is not a major, long-term barrier. As quality community programs continue to be developed and a good track record of stable funding is evidenced, parent concerns will diminish. However, this is a major political issue for now and the immediate future.

PUBLIC ATTITUDES

Historically, institutional services have been perceived as necessary by society at large. In addition, there has been some lack of acceptance of community-based alternatives.

Consequences

Negative public reaction to deinstitutionalization could result in restrictive zoning laws, defeat of local levies for funding of community programs, etc.

Solution Strategies

The short history of the deinstitutionalization movement shows that public attitudes can be changed in a positive direction. Possible strategies include:

- o Developing smaller (more easily accepted) programs
- o Increasing local involvement and local control of programs, and planning
- o Increasing acceptance of permissive zoning codes

Conclusions

Public attitudes is not a major, long-term barrier. As quality community programs continue to be developed, public acceptance of such programs will increase. Increasing local involvement and control in planning and operating service programs will assist in overcoming negative public attitudes.

COMMUNITY RESOURCES

The shift to a community-based service delivery system requires a dramatic increase in the number of trained personnel in local MR/DD programs and in generic service agencies. Personnel resources become increasingly more important as more severely handicapped persons return to their home communities. At a minimum, each person must be assured of receiving no less service (both quantity and quality) in community programs than they received previously. Historically, Ohio has not been able to rely on the availability of adequate generic service resources. Nursing homes and other large, institutional-type community programs have usually been self-contained programs, and made minimal use of community resources. Smaller, more integrated programs will rely much more heavily on the availability of generic services (medical, dental, psychological, etc.).

Consequences

If adequate community resources are not available, two problems could occur: (1) some persons will continue to be placed in institutions, or remain institutionalized, because community programs to meet their needs "are not available" and; (2) some persons might be placed in community programs that would not be adequate to meet their needs.

The first problem will result in a slowdown in the deinstitutionalization process. The second problem, which is more likely to occur, will result in a violation of persons' right to adequate and appropriate services.

Solution Strategies

At least four major strategies are needed to deal with the problems described above:

- o Attention should be focused on the development of adequate community services.
- o The state should ensure that adequate standards and monitoring mechanisms, including consumer evaluation, are developed to ensure quality service provisions.
- o A consortium of state agencies should be formed to influence colleges, universities, and other generic agencies in their development of appropriate pre- and in-service training programs (mobile training teams should be developed to provide both training to generic providers and direct service to clients until adequate community resources are developed).
- o Some counties, especially those in rural areas, need to develop the ability to provide financial incentives to attract competent personnel, or to establish multi-county programs.

Other strategies suggested include:

- o Initiating a state billing system for providing "upfront" funds to pay Medicaid providers
- o Revising rules and regulations so that daily maintenance, habilitation, and rehabilitation services can be provided by a wider range of trained and experienced staff
- o Establishing a system of family supports to assist families in obtaining needed services

Development of adequate and comprehensive community resources is a long-term process, but it should be possible to

synchronize this development with the gradual phasing out of institutional services.

Conclusion

Community resources is not a major barrier to adoption of the working assumption. However, if as institutional services are phased out, adequate services are not available in the community, progress will stop. Availability of community resources is not a barrier to planning and initial implementation but, unless intensive efforts are made, it could very well function as a major, long-term barrier.

FUNDING RESOURCES

The phasing out of institutional services, especially of developmental centers, has a profound impact on how the state's financial resources are allocated. A lack of funds for community programs has frequently been cited as a barrier to deinstitutionalization. Equally important is the issue of cost-effectiveness of service provision. Given the history of community services, it is extremely important that, in addition to being adequate, the funding base must be seen as permanent.

Consequences

It will probably not be possible to make the transition to a community-based system without some initial increase in costs, which is an inherent problem in a "dual" service system. Also, it will not be possible to develop a comprehensive system of community resources without transferring funds from the institutional system.

Solution Strategies

As is the case with most of the other potential barriers, the funding issue requires both short- and long-term solution strategies. Some short-term strategies include:

- Increasing the use of Medicaid funding for community-based services to help eliminate one of the disincentives to deinstitutionalization
- Increasing joint funding/programming to distribute cost more equitably between state and local human service agencies
- Making changes in rules and regulations pertaining to Purchase of Service so that adequate, flexible funding

is available to meet the needs of persons with severe disabilities

- o Using Department rules, regulations, and the Certificate of Need review process to establish standards for community-operated nonprofit, and private for-profit facilities

- o Reducing funding and capital formation disincentives for residential development by nonprofit groups, which mitigate against developing smaller facilities

Major long-term strategy(ies) must deal with the issue of maintaining state responsibility for seeing that adequate services are provided while, at the same time, developing a funding formula that provides an appropriate balance of federal, state, and local funding. If counties perceive the phasing out of institutional programs to be a means for the state to escape from its current financial obligations, the plan will fail.

Conclusion

Based on the limited amount of cost-effectiveness data now available, it seems clear that quality community alternatives can be developed that are not more expensive than comparable institutional services. There is no reason, based on available cost data, to prevent adopting the working assumption and beginning the planning process. Costs must of course be monitored and will obviously result in revisions to the plan, but this is no reason not to begin.

LEGAL CONCERNS

The Ohio Revised Code (ORC) outlines the service responsibilities of the Department of Mental Retardation and Developmental Disabilities. Currently, it is not clear what, if any, legislative changes will be necessary to phase out institutional services gradually.

Consequences

A lack of legislative authority could hinder, at least initially, the deinstitutionalization process.

Solution Strategies

Analyze ORC and, if necessary, make changes that allow for:

- o A mechanism to assure provision of service, even if the state is no longer a direct provider of service
- o Maintenance of a pinpoint of responsibility at the state level

Conclusion

Legal concerns do not have the same substantive impact as do the other issues. If the other issues can be resolved, this problem will surely not be a major one. However, real or "supposed" legislative mandates might be used by opponents to slow the deinstitutionalization process.

COORDINATION/MANAGEMENT

The phasing out of institutional services requires a redefinition of the responsibilities and management functions of state and county programs. An effective administrative structure is necessary for maintaining a comprehensive community-based service delivery system.

Consequences

The potential consequences of problems in coordination and management are difficult to describe. It is fairly easy to determine whether sufficient funds are available and whether adequate numbers of trained personnel are available. It is much more difficult to judge whether a service system is adequately managed and well-coordinated. However, it is not difficult to see the negative effects of a poorly coordinated service system. Lack of a coordinated system results in:

- o Gaps in the service system
- o Inflexible use of funds and personnel resources
- o Fragmented service plans
- o Inadequate monitoring of service provision
- o Inappropriate duplication of effort

System Barriers

A "non-system" approach results in either a major barrier to continued community development or a large decrease in the quality of service provided.

Solution Strategies

Redefining the responsibilities and management functions of state and county programs probably will be the most difficult one to overcome. Systemic problems require systemic solutions. It is far too simplistic to direct administrators to "develop a well-coordinated service system". Development of such a system requires major changes in:

- o Regulatory authority
- o Funding sources
- o Flexibility in utilizing funds
- o Decision-making responsibility
- o Case management responsibilities
- o Pinpoints of service responsibility

Additional strategies include:

- o Using existing technology (specifically computers) more effectively to assist in planning and monitoring
- o Using the Individual Habilitation Plan (IHP) as the basic document for planning and evaluation
- o Developing more effective means for advocates to influence the system
- o Building normalization criteria and legal rights into standards, regulations, and monitoring systems
- o Developing mechanisms to coordinate fragmented service delivery at the local level (county/multi-county)
- o Establishing mechanisms to improve the interface between community residential facilities and County Boards of MR/DD
- o Strengthening the role of the Department of MR/DD in monitoring community programs
- o Coordinating planning at the local level to guide future system development

o Strengthening the role of the Department of MR/DD in helping coordinate planning at the local level

Conclusion

The current lack of an effective administrative structure serves as a barrier to continued community development and a major barrier to the gradual phasing out of all institutional services. This barrier does not require rejection of the working assumption, but does have to be the first major variable considered in the planning process.

INDIVIDUAL RIGHTS

Persons currently residing in institutions, or those who may be in need of some form of "long-term care", have certain rights and needs. Plans for phasing out institutional services must ensure the protection of a person's rights as well as ensure that the person's needs are being met.

Consequences

If parents, the public, and professionals were to perceive that individual needs were being sacrificed in the name of institutional depopulation, there would be a powerful political backlash. This backlash is already apparent in the many documented cases of "community dumping programs".

Solution Strategies

As was stated earlier in the Parents' Rights section, no one has a right to live in an institution if his or her needs can be met in a less restrictive setting.

Some persons may wish to remain in institutions. One must ask if such persons have ever experienced more integrated residential alternatives. Given that the phasing out of institutional services will be gradual, it will be possible to temporarily respect the wishes of most, if not all, of these individuals. However, once the institutional population gets below the level of economic feasibility, the remaining residents must be moved.

Conclusion

Given the gradual phase out of institutional programs, and the number of persons who have lived in institutions for a long time and would likely wish to continue to do so,

consideration of individual rights is not an immediate barrier to accepting the working assumption.

COMMUNITY PROGRAM CAPACITY

The problem of community program capacity is not actually separable from those of funding, personnel resources, and system coordination. Given that these problems are to be dealt with effectively, program capacity will not be an issue. However, it is important to note that the complete phasing out of institutional services, both developmental centers and community-based institutions, requires a significant increase in the capacity of community programs. Many of the persons who have already left developmental centers have returned to live independently, in the community with their families, in room and board homes, or in nursing homes and other community institutions. Most of the severely disabled residents remaining in institutions will not return to their families and, therefore, the plan calls for the development of a large number of small, community-based living options.

GENERAL CONCLUSIONS

No major problems preclude Ohio from adopting the working assumption and beginning to plan for a community-based service system, without institutional services.

Many problems could ultimately cause such a plan to fail or require modification. However, this does not mean that Ohio cannct begin the planning process.

COMMUNITY INSTITUTIONS

A growing controversy in most states centers around the present and future role of smaller institutional programs located in the local community. Examples of such programs are nursing homes (ICF), nursing homes for persons with mental retardation (ICF/MR), and specialized care facilities.

Many states have such programs as the major means of depopulating their large institutions. For example, in the 1970's, Wisconsin had more people institutionalized in nursing homes than in state-operated developmental centers. In FY 1979-80, more than half of all the moves out of institutions in Florida were to large community-based ICF/MR programs. Ohio has also witnessed a rapid growth in the number of large community institutions. For example, in January 1983, there were 81 ICF/MR facilities with a total 2,715 beds. Of these, 2,473 were in facilities of 16 beds or more. Approximately 91% of the individuals living in an Ohio community ICF/MR program were living in facilities with 16 or more beds.

Four serious objections have been raised to a "transinstitutionalization" strategy:

- In some community-based institutions, conditions are at least as dehumanizing as in large state-operated centers.
- Some persons have been placed in community-based institutions (such as nursing homes), which are not designed to meet the needs of persons with developmental disabilities.
- Given that there are more integrative alternatives possible, placement in a community institution, even one located in the person's home community, is unnecessary and inappropriate.
- The development of large community institutions merely transfers the problems associated with congregate care from the state to the local community.

Most of the issues raised under the section on Planning Principles are applicable here; only the differences will be described.

Least Restrictive Environment: Clearly community-based institutions will be smaller and probably closer to the person's home than the present state-operated institutional facilities. However, smaller four- to six-bed ICF/MRs (as operated in Michigan and a number of other states) represent a less restrictive option.

Right to Services: It is difficult to defend community institutions as the best learning and service environment.

Normalization Principle: Community institutions clearly facilitate physical integration. However, they have little, if any, impact on the person's social integration in the community.

Equal Justice: Can we allow funding priorities to determine whether some persons are transinstitutionalized to community institutions while persons with similar needs are served in smaller, less restrictive settings?

Respect for Human Dignity: Community institutions such as nursing homes or large specialized care facilities, are not positively valued by society. The "best" nursing home in Ohio does not have young, nondisabled persons on its waiting list. Placing disabled persons in community institutions further stigmatizes them; if this is necessary to meet their needs, then it must be done. If less stigmatizing, more positively valued alternatives are possible, they must be used.

Dual System

Developmental Assumption: Community institutions, like all institutional settings, tend to congregate persons with special needs and segregate them from normal community activites, which is not consistent with the developmental assumption.

Effectiveness and Economy: One advantage to the institutional strategy has always been described as economy of scale. Some persons contend that the most economical way to serve persons with severe handicaps is in relatively large numbers (30-100 persons). Yet, this advantage has never been supported by cost data. In fact, a number of states have developed an alternative approach—using small group homes. The cost data from these programs show that quality, appropriate services can be provided at a cost equal to or less than community institution costs.

As delineated in Position Paper No. 2 on residential services, community institutions do not play a role in long-term plans for residential services. Therefore, it will be a serious mistake to continue the development of community institutions. Tremendous sums of money would be necessary to establish a sufficient number of community institutional facilities—funds which will have to be diverted from the development of smaller, more integrated home-center alternatives. The continued development of large community institutions will merely perpetuate the problems associated with Ohio's institutions by transferring those problems to the community. Although community institutions may be newer and better equipped than older state-operated facilities, it is important to remember that the goal is to promote the physical and social integration of persons with developmental disabilities. Small, more integrated home-centered alternatives provide a more likely environment to achieve that goal. To facilitate the movement to a service system without institutional services, the state needs to begin now to develop plans for the eventual phase out of community institutions.

PHASE OUT OF DUAL SYSTEM

During the past several years, significant progress has been made to improve the availability of community-based programs in Ohio. The growth of the state's Purchase of Service program, the passage of Amended Substitute Senate Bill 160, (ASSB 160), which expanded the role and responsibility of County Boards of MR/DD, and increased funding for community programs, are indicative of the state's effort to improve service availability at the local level. While this progress has been significant, the current dual service system of separate community and institutional programs raises organizational barriers to the continued development of effective services. These barriers result in:

- o Separate and poorly coordinated programming/budgeting of institutional and community-based services

- o Over-use of costly institutional services for many persons with developmental disabilities whose needs might be met more appropriately in a community setting

- o Unclear roles for the Department of MR/DD, County Boards of MR/DD, and state-operated institutions in: (1) service delivery (2) fiscal control (3) system management and accountability, and (4) client responsibility.

The Deinstitutionalization Task Force believes that a "single- focus system" should be developed, which would assure continuity in services and flexibility in the range of services available to meet the needs of persons with developmental disabilities. This continuity and flexibility can only be accomplished, in the long run, when responsibility for all client services is located at the county or multi-county level. Therefore, it is proposed that a single, unified system of services be established that coordinates the resources presently available and locates client responsibility in the community, regardless of where or how the service is provided. Although the Task Force's long-term plan calls for the phasing out of state and community institutions, this process cannot be achieved immediately. A significant time period will be necessary for planning and developing implementation strategies to address the barriers delineated in this report. However, movement toward a unified service system should begin now, to eliminate the negative consequences of the present dual service system. A first step in that process is elimination of the dual client responsibility that presently exists. The following recommendations are proposed:

RECOMMENDATIONS

- o **The Department of MR/DD should delegate responsibility for the provision and planning of services to County Boards of MR/DD.**

- o **Comprehensive planning by County Boards of MR/DD should include plans for the delivery of services to county residents, persons placed under the Purchase of Service program, and county residents currently residing in state developmental centers.**

- o **Current state developmental centers, as long as they exist, should be viewed as a community resource to be accessed when the service they are equipped to provide is not presently available in the county.**

- o **The Department of MR/DD budgeting process should be changed to allocate state resources to County Boards**

of MR/DD for the purchasing of services from state developmental centers for each county's clients.

- Increased funding should be provided to further expand local services to meet the needs of those persons currently residing in state facilities who could benefit from community services.

- Persons who are seeking admission, or who are referred to a state developmental center should first be evaluated by the County Board of MR/DD to determine if their needs can be met more appropriately in a community setting.

- A cost-sharing mechanism should be developed and phased in over a four-year period, that equitably distributes the cost between the state and the local community for nonreimbursable costs (e.g., non-ICF/MR) of maintaining a person in a state facility.

- Department of MR/DD planning efforts should be more strongly geared to moving the state toward developing integrated community-based services.

- These proposed changes should take place as a jointly negotiated shifting of responsibilities and accountability, which should occur over a period of four years (1984-1988).

REFERENCES

Apolloni, T., Cappuccilli, J. & Cooke, T. (1980). Achievements in residential services for persons with disabilities. University Park Press.

Boggs, E.M. (June 5, 1981). Testimony on the Medicaid program and mentally retarded people. The Subcommittee on Health and the Environment of the Committee on Energy and Commerce, U.S. House of Representatives. Washington D.C.

Lakin, K.C., Bruininks, R.H., Doth, D., & Hauber, F. (September 1982). Sourcebook on long term care for developmentally disabled people. (Center for Residential and Community Services Project Report #17). Minneapolis, MN: University of Minnesota.

Laski, F. (1980). Right to services in the community: Implications of the Pennhurst case. In R.J. Flynn & K.E. Nitsch (Eds.), Normalization, social integration and community services. Baltimore: University Park Press.

Martin, J.E., Rusch, F.R., & Heal, L.W. (1982). Teaching community survival skills to mentally retarded adults: A review and analysis. The Journal of Special Education, 16 (3).

McCarver, R.B. & Craig, E.M. (1974). Placement of the retarded in the community: Prognosis and outcome. In N.R. Ellis (Ed.), International review of research in mental retardation, 7. New York: Academic Press.

Ohio Department of Mental Retardation and Developmental Disabilities. (December 1982). Annual financial and statistical report. Fiscal year 1982. Columbus, Ohio. Author.

PCMR. (1978). Mental retardation: The leading edge. Report to the President 1978. Washington: U.S. Government Printing Office.

Pilewski, M.E. & Heal, L.W. (1980). Empirical support for deinstitutionalization. In A. Novak & L. Heal (Eds.), Integration of DD individuals into the community. Baltimore: Paul H. Brooks.

Touche-Ross. (1980). Report on costs of community-based and institutional services in Nebraska. Unpublished manuscript.

Wieck, C.A. & Bruininks, R.H. (1980). The cost of public and community residential care for the mentally retarded people in the United States (Project Report No. 9, Developmental Disabilities Project on Residential Services and Community Adjustment). Minneapolis, MN: University of Minnesota, Department of Psychoeducational Studies.

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